



# Second Wind

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## NEWSLETTER

**August 2005**

*PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, nor relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.*

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Key words: Norway, Sweden, Retinoic Acid Update, Traveling with Oxygen, Successfully Aging

**If you are wondering why** this newsletter is so late let me brief you about a few of the things that have



The Tromsø Arctic Chapel at midnight

been happening. Last June, 24 hours after leaving sunny Los Angeles, I flew low over spectacular blue fiords edged with jagged snow-covered peaks while landing in Tromsø, Norway, 600 miles above the Arctic Circle.

This is so far north that even the Vikings never got that far! Norway is arguably one of the most beautiful countries in the world, if you are thrilled by wild, rugged scenery, but not too fussy about having perfect weather.



View from my Tromsø hotel balcony at midnight.

was my 3rd visit. The hospitable Norwegians treated me like an old friend, as well as a visiting celebrity. Who could ask for a more gracious welcome! The University Hospital of Northern Norway is the northernmost university in the world and its location on top of the world matches its academic achievements. The quality of pulmonary rehabilitation, medicine and research going on in this town of 60,000 people is very impressive, easily matching the standards of other more renowned centers you might think of.

I was there during the time of the midnight sun.

For 2 months the sun never sets, and for at least one more month it is always light, even at night. Of course in the winter there are 3 months of darkness! The loyal residents of Tromsø remind visitors that they then have the moon, the stars and the Northern lights to

enjoy during the dark night of winter. Besides, extensive outdoor lighting includes even the cross-country ski trails!

Norwegian June seemed cold to a Southern Californian and I needed the beautiful Norwegian sweater presented on arrival. Much more useful than a lei would have been!

It My long sleeve tops, plus a jacket, weren't warm enough. But can you imagine the thrill of seeing the sun shining at midnight on the snow-covered peaks across the fiords? Nobody slept much with the sun out all the time, including me.



I had the pleasure of speaking to the great staff and rehab patients in the Tromsø Elizabet Senter rehabilitation facility. Their five-hour rehab day includes lunch with the staff in a glass-walled cafeteria looking out at the spectacular scenery.

All meals in Norway, even hotel breakfasts, seemed to include pickled herring, smoked fish of all kinds, and many variations of wonderful wild salmon along with boiled potatoes. Sort of a tough if you are on low sodium diet. All patients had the latest portable liquid oxygen equipment. They were as interested in American rehab and ways of doing things as we are in theirs. And almost everyone also talked about a relative they had in the States, so conversations were lively. Much of their rehab, started around 1990, is based on our programs, which started many years earlier. You would find everything comfortably familiar. Tromso is way ahead of us, however, in that they are concentrating on early intervention and now rarely see anyone with an FEV<sub>1</sub> as low as 40% of predicted. They may have learned about rehab and portable oxygen from us but now it is time for us to emulate and learn from them!



View from Dr. Hjalmarsen's side porch.

We drove even further North to the Skibotn. This is an inpatient facility for various conditions including COPD. There was a fee but it seemed like wonderful value for the location and services offered. It was adjacent to a fiord and surrounded by alpine forest. Fish are guaranteed to jump on the hook as soon as you cast a line, ready for an evening barbeque.

From Skibotn it was on the trip of a lifetime as we drove even further North to the Elgin Alps. You've never heard of them? Neither had I, but they should be declared the 8th wonder of the world! Seeing these snow-covered peaks plunge straight down into the fiords was an absolutely breathtaking experience shared with almost no one else on these deserted roads. Dr. Audhild Hjalmarsen also drove us up over the Finnish border onto the tundra where some Saami native people (Laplanders) still herd reindeer. The Saami are well educated and medically sophisticated. I once had

a marvelous slide of a Laplander herding reindeer with the aid of his portable liquid oxygen!

There is only a small sign marking the border of these two sister countries and the friendly Finns let the Norwegians drive medical supplies over this shortcut route to Russia. There are no problems with the Finnish border guards, who know all the doctors and approve of their humanitarian efforts. The Russian guards, however, are a different story, often demanding bribes despite knowing how desperately their country needs this aid.

After 5 wonderful days in Tromso and points even further north, several of us flew about 1,000 miles south to picturesque, cold, rainy Trondheim. It was here that the 42nd Nordic Lung Conference was held. I had the pleasure of joining other pulmonary health care professionals as I spoke on pulmonary rehabilitation in the United States.

Then I confess to playing hooky for the weekend. I flew down to Bergen for 2 days to take the famous *Norway in a Nutshell* train trip in addition to cruising some fiords. Again, spectacular scenery despite the cold and the rain.



I was just getting used to it when I flew to Stockholm. The heat and humidity when I got off the plane reminded me of July in Connecticut. The Swedes loved it! I stayed with our friends, Dr. Margareta Emtner's family, in their 3rd floor bedroom. My bathroom was on the first floor. My glasses were always on whatever floor I was not. We also walked briskly to parties, to dinner, or to the nearby woods to pick wild flowers so you can be sure getting enough exercise was not a problem. There was lots of good-natured teasing and funny stories about Americans who expect to drive everywhere. I deserved it!

To speak at Uppsala University I had to walk more than 2 miles since I was leery of riding a bike like everyone else. But I learned my lesson last year. This time I wore unfashionable walking shoes rather than heels. Heels are NOT the shoes of choice when you have to walk a couple of miles over cobblestones. And everyone walks



or rides bikes, not matter how old or young or elevated their station in life. Tiny pre-schoolers stride down the streets with a pole in each hand, preparing for cross-country skiing, which is the national sport. Older people needing a cane, always use two instead of one, which makes wonderful sense and body mechanics. At first, it seems strange to walk everywhere, instead of jumping in the car, but I really missed this lifestyle when I got back Southern California.

I have lots and lots to tell but you are probably interested in hearing about the renowned Swedish and Norwegian systems of health care and cradle to grave security. And it is very good care. No one is rich and no one is poor. However, Scandinavians will tell you it is not as ideal as we so enviously believe. They pay for all their dental care. There is a \$500 deductible before you get medicines in the formulary of your particular area. As with

HMOs in this country, you do not go to the doctor of your choice, unless you have private insurance. If you need surgery like a hip or knee replacement, there is often a wait of 6 months. MRIs have equally long waits unless you have additional private insurance, as most people do. And they pay for this “free” health care in a way that no American taxpayer would tolerate. There is a 25% sales tax on EVERYTHING including food, which helps make Scandinavia an expensive place to visit. This is on top of their income tax which averages about 50% but can go up to 95% if your income is high enough. Both Norway and Sweden have a serious, familiar-to-California, problem with immigrants and refugees. Because of this financial burden, there have been reimbursement cuts to hospitals as well as to other medical benefits, much to the dismay of the medical community. Their standard of medicine is excellent but they will remind the visitor that they are paying for it.

I had a wonderful three weeks in these two great countries. They are clean and beautiful with educated, friendly, honest people who usually speak English, thanks to American TV. I was invited into homes, and to parties, and surrounded with warmth, fun, friendship and great

conversations. As always in my travels, my life was enriched with new insights and information. If you get the chance to visit these countries, and are prepared for the expense, I promise you a wonderful experience with the best of health care available, should you need it. Many, many thanks to all the wonderful people I met! 🙏🙏🙏

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*Thanks to Kathleen Norulak for finishing the newsletter last month!*

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*Virginia Brown made a memorial donation in memory of Connie Hecht. Colleen Sticht made a memorial donation in memory of Frederick Carson.*

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*We have received many letters asking for an update on Retinoic Acid. Our thanks to Dr. Tiep who has graciously provided us with the following information*

### **Retinoic Acid: The Promise of Lung Regeneration**

*Brian L Tiep, MD*

*Respiratory Disease Management  
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*Pomona, CA 91767*

When dealing with a disease destroys lung tissue and the ability to breathe, the concept of disease reversal and lung regeneration is most welcome. We often cast these concepts aside as being too far in the future to benefit present disease sufferers. However, two scientific investigators, Drs. Gloria and

Donald Massaro have raised our hopes that this might be possible - and sooner than we think. They created an animal model that seemed to work. They first caused rats to develop a rat version of emphysema. They then gave these rats retinoids (retinoic acid), which are substances related to vitamin A. Retinoids are well known for their ability to regulate normal lung growth and development and emphysema is a process that destroys lung. The Massaros became enamored with notion that retinoids might be able to regenerate lung growth and basically cure emphysema. They gave these rats a retinoid drug called all-trans retinoic acid (ATRA). They found what appeared to be regeneration of normal lung from emphysema. The regenerated lung had the structure of normal lung and appeared to function normally as well.

As might be expected, this development created quite a stir in the medical community as well as patients. Perhaps this could be the beginning of a lung regeneration method for people with emphysema. It was also very exciting that a substance so closely related to vitamin A might become a possible cure for emphysema.

A pilot study was carried out in 20 emphysema patients, and published in American Journal of Respiratory and Critical Care Medicine 2002 March (Vol 165 (no 5) p.718-723. They found

that during 3 months of treatment the drug was well tolerated and associated with only mild side effects such as headache and muscle aches and pain. Unfortunately, there was no change in the patient's lungs as measured by X-ray CT scan or lung function. Among the findings of that study and other related studies was that the drug may have had some effect on the formation and progression of emphysema, perhaps a suggestion of change in lung function, and some biochemical changes that could impact the disease process. These retinoids appear to be safe although more studies are needed to fully verify their safety. The original promise of this line of research presently remains *unfulfilled*. *However, researchers are learning more* about these compounds from human and animal studies and this line of research could eventually lead to compounds that will regenerate lung tissue. Please stay tuned.

Meanwhile, you can maximize your ability to live happy and effective lives in spite of COPD. Ask your doctor to refer you to pulmonary rehabilitation. While you are at it, ask your doctor for a rapid action plan in case of a flare-up (otherwise called an “attack”, an “episode”, an “infection”). Live an active life.

A few simple suggestions could help:

1. Every day – get up and get dressed

2. Take your medications (and oxygen) as prescribed.
3. Make sure that you use good technique when taking your inhalers
4. Cough and clear secretions – if you have them
5. Do your pursed lips breathing
6. Walk daily
7. At the end of your walk – check to see if you are having a flare-up – are you more short of breath and is there a change in your sputum?
8. If you have a flare-up or think you might be having one, call your doctor immediately and start your rapid action plan. This may prevent hospitalization.

*Again, stay tuned; learn all you can about your disease; live an active life; remain in control of your disease.*

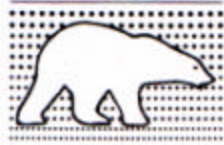
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For more than ten years your editor has struggled to provide you with information-laden monthly newsletters. The time has come to join many other newsletters and become a quarterly publication. As a volunteer, I am finding that I just can't keep up with my personal responsibilities as I answer the many demands and needs of PERF. I hope to have a quarterly newsletter out in early November. If I catch up with other responsibilities, and recuperate from writer's block, you may hear from me sooner. Until that time, stay well! 🙏🙏🙏

*Best wishes to all,*

**Mary Burns**

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Senior Moderator

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July 2004

Dear Friends:

**On the Road Again!**

Most of us like to travel , for leisure or business. The constraints of needing oxygen may be limiting, but things are improving a lot. New technologies are making land and sea travel quite possible for most. An expert on traveling with oxygen is Pete Wilson. Look him up at [petewilson@portableoxygen.com](mailto:petewilson@portableoxygen.com) . He has a great CD that gives all the specifics of what you need to put oxygen in your car, or take on the train or boat.

I have had success with the Liberator 10, a small liquid system, that you can strap into the back seat of your car or van. It lasts about 5 -7 days. You can refill your Helios, Spirit, or Escort from it. Or the larger liquid system ,the Marathon, that gives you about 18 hours of ambulatory oxygen per f ill, depending on your flow needs.

Other options are the small portable concentrators, that power from your car, or electricity. The LifeStyle, Inogen, and a new one soon to be released, the Oxytech, give pulse dose of oxygen that is sufficient for most patients. You can conserve your liquid supply, using a small concentrator while driving.

Hopefully the small concentrators will soon be allowed for air travel. They are perfectly safe, and should be approved without further delay. Lots of lobbying has been done already to help make this happen.

So, plan to get out more often and see the wonders of nature, or visit family and friends. I just returned from the Annual Aspen Lung Conference, which discussed the latest new research in COPD. There are lots of exciting developments that will soon be translated into new therapies. Aspen is at 8500 feet. The passes are 12,000 feet. I did well with my light weight liquid portable system. Yes, it's great to be "On the Road Again".

I'll be in touch next month.

Sincerely yours,

**Tom**

Thomas L. Petty, M.D.  
Professor of Medicine UCHSC

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August 2005

Dear Friends,

### Successful Aging!

The aging process is of great interest to scientists and to all of us. The process is complex, a function of all higher animals. There is an internal "clock" that determines the length of life for all species. Not the exact length, but a range. In general, all animal groups die in about six times the interval between birth and maturity. In humans maturity is complete about aged 20. Thus the extremes of life may be near 120 years. Indeed there is one well documented person who lived to age 122. Sixty-five people in the world have good proof that they are 110 or more.

Some insight about aging comes from cultures of cell growth under "test tube" conditions. Young cells live much longer than old cells, in the same growth environment and with the same nutrition. The "clock" just runs down and stops. Same thing with animal cloning. The cloned animal is as old as the animal from which it was cloned, when born. Thus the clock has already been running. Cloning will not increase longevity.

Life expectancy has been steadily increasing in the past 100 years, not because the length of life is getting longer, but because good health habits and modern medicine are reducing the premature morbidity and mortality of modern existence. Avoiding smoking and excess alcohol, keeping a lean body weight, and exercising are clearly factors in increased longevity. So is the avoidance of life shortening diseases, mostly the infectious ones, such as tuberculosis, typhoid, and cholera in this country. Reducing traumatic deaths from accidents or warfare is another way to stop premature mortality.

Today the boy born in 2001 can expect to reach 74 on average. Girls will live to 80 if present predictions hold. How can you be sure to live to 100? An old joke I learned in medical school goes like this. "If you want to live to be 100, do not drink or smoke at all. Do not take any chances. Have sex only for pro creational purposes. Do not eat rich food, and do not travel unless you must. The fact is that you will not live to be 110, it will just SEEM like it!" This joke always gets a laugh.

Stress is also a factor in premature morbidity. How to avoid stress is difficult to do, particularly in a complex society. It is how you learn to handle stress that is more important than avoiding it. Also staying connected is important -- connections with spouses or other partners, family, friends, and church. Loners don't survive very well alone. Also the value of humor must be always remembered.

Keep smiling, loving and living is my advice for us all!  
I'll be in touch next month.

Your friend,

**Tom**

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